

## **Bismarck Session – Written Feedback**

1. In what ways do you find information about programs and services available to you and your child?

- State very hesitant about releasing any information to help us
- From other parents (3)
- Case Manager
- Agencies like hospital and schools
- Improvement: Hire parents to coordinate information and get info to patients  
Advocate for additional state family subsidy dollars  
Why wouldn't we request more?
- Magic Foundation
- Internet
- Usually through the school or just what I do on my own
- Word-of-mouth

2. Who is the service provider who primarily coordinates care for your child? (by title or profession)

- We as parents need agencies to coordinate hiring and training people
- Our Case Manager helps (2)
- Ourselves (2)
- Dr. Sirwiwan, Neurologist
- Mainly my husband and myself
- Dr. Ocejó – her Pediatrician Doctor
- I am the main person who does her care
- Through the school, her classroom schedule and IEP team

3. What other health care professionals or service providers assist in organizing or coordinating care for your child?

- Physicians
- Parents
- Case Managers
- Pediatrician
- She is in early intervention
- Her OT

4. What do you like about the way your child's care is coordinated?

- What is coordination?
- I don't feel I see a lot of coordinating
- Not much – I do a lot for her by myself
- I am lucky to have a great classroom teacher who works with my daughter

5. On a scale of one to five, with one being poor and five being excellent, how well do you feel your child's health care needs are being met overall?

**5**

**Human Services 2-3**

**Physicians 5**

**By our family 4-5**

**Insurance Company 2-3**

**3**

**3**

**1 ½ -no one here in ND knows a lot about what Russell Silver Syndrome is**

**2**

6. What methods are currently in place to help assure quality care for your child?

**-Parents**

**-None that I can think of**

**-We are pretty much on our own when it comes to the care of our daughter**

7. Have you gone out of state to obtain specialized services for your child? If so, where did you go and for what reasons?

**-Yes – Dr. Appointments in Minneapolis**

**-Yes – Children's hospital in Houston for cardiac services**

**-No (2)**

**-Yes**

8. In what ways have you or your child received support or services from the Department of Human Services, Children's Special Health Services unit?

**-Case Manager**

**-Family subsidy**

**-Easter Seals – Respiratory Care**

**-I knew about it, but there were no services that fit our needs**

**-DD Case Management**

**-Medicaid**

**-We have received no services.**

**- I have never heard of Children's Special Health Services**

9. What types of financial assistance are you aware of that are available to support the special health care needs of your child?

- Family subsidy
- We could apply for MR-DD/DDCM and then be eligible for family subsidy in MA and family support
- Medicaid
- I have never gotten any information

10. Have you ever been denied health care services because of financial barriers?

- Yes (2)
- No – we are very lucky
- No (2)

11. What one recommendation do you have for improving the care provided for your child and family?

- Complete reversal of attitude of Human Services and the Legislatures
- Change their attitude
- No good coordination occurs – someone to help in this process would be needed
- Assistance to families in the area of problem solving through difficult times
- More funding in the DD Program
- Develop a comprehensive system of care for all children with special health care needs, not just kids with MR/DD – including MA coverage
- Improve DD case management's knowledge or willingness to help
- I would like for whomever to really look at my daughter instead of just look at how she is now. She has NO choice but to get medical needs. Without medical care she will suffer a lot in life! She needs to have people be aware of what she has and know what her syndrome is. We are at a loss here and need help! Where do we go from here? HELP!
- More communication between caregivers and the state
- Better attitude from officials when inquiring
- To help families and change financial guidelines